

Doctors, ethics and special education

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Abstract

This discussion paper is drawn from a qualitative research project comparing the effect of special and ordinary schools on the lives of children, young people and their families. Special schools are recommended by health professionals who seldom know how ineffective these schools are. We question the beneficence and justice of health professionals' advice on education for children with disabilities and other difficulties.

Cooperation with local education authorities (LEAs) plays a considerable part in the work of community paediatricians, clinical medical officers, therapists and other health professionals encountering children with "special needs". The "needs" range from physical disability and sensory impairment to learning difficulties and emotional or behavioural difficulties. This cooperation involves routine administrative problems, but it raises broad ethical issues too, particularly in respect of current tendencies in state schooling towards the integration or inclusion of these children in mainstream schools and classes.¹ (Journal of Medical Ethics 1998;24:49-55)

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We discuss below a web of interrelated issues. "Medical ethics" and "educational ethics" are not the same thing, nor can one be reduced to the other; yet both medical and educational advice contribute to decisions about school placement. Possible conflicts arise where different agencies are involved, and no single rule of good and bad practice can determine the decisions; out of such conflict arise ethical dilemmas. Health care professionals may encounter problems about boundaries. On the one hand they may step outside their role uninvited; on the other, their strictly medical advice is used by other agencies and may therefore be misused. Health professionals sometimes give advice in ignorance of matters which are relevant to, but beyond, their own strictly professional remit; this ignorance may be neutral (not knowing something) or it may have an ethical component (for example, not knowing that which one has a duty to know, or claiming to know when one does not).

We examine these issues below, interspersing discussion with evidence from our own research. Most of this has been conducted, separately or together, in local authority areas at extreme ends of the spectrum. One area is an inner-city area (East City), where currently 89% of children with "statements" of their special educational needs are supported in mainstream classes and most special schools have been closed, and resources and staff transferred. The other area is a county area (West County) where levels of separate special and residential school provision remain high. An extensive literature discusses special schools and inclusive education, but little is known either of the pupils' or of the parents' own views. Our recent research investigates the views and experiences of pupils with physical, sensory, emotional and learning difficulties, and of adults responsible for them. We observed daily activities in 22 schools and conducted in-depth interviews with 45 young people aged from 7 to 17, with their parents and some other family members, and with school governors, local education authority members and officers, and school staff.² Names have been changed to preserve anonymity.

Historical developments

The relationship between medical and educational approaches to children with disabilities and other difficulties has a long history which we can only touch on here. The educational profession has veered between optimistic, often successful experiments in teaching such children, and disclaiming responsibility for many of them as "ineducable"; it was only with the 1970 Education (Handicapped Children) Act that education took responsibility for children with severe learning difficulties. The medical profession has demonstrated a more consistent philosophy of care, recognizing all such children as its responsibility but also, perhaps, having a parsimonious view of their developmental potential.

After 1945 the legislative emphasis was on categories of "handicap" and "subnormality", with non-standardised assessments and segregation. The process of assessing and segregating was rough and ready. If a recommended place was not available locally, the child might be sent out of the

area, often to a remote residential special school. Local education authorities employed doctors to determine the exact categories into which children fitted. Parents were instructed to present their children for examination and were fined if they did not. It was quite usual for a paediatrician to tell a parent whose baby was only two weeks old which special school the child would attend. Neither parent nor pupil had the right to be consulted over placement.

The 1981 Education Act (since replaced by the 1993 act) was a watershed. It gave parents certain rights, including the right of appeal over where the child was placed, the right to challenge professional judgments, and the right to contribute advice alongside professionals to the child's "statement" of special educational needs. The statement, which summarises the extra provision required for the child, has the precise status of a legal document. The act also made it "the duty of the authority ... to secure that [the child] is educated in an ordinary school".³ Commentators paraphrasing the act often insert after this the words "wherever possible". This is misleading, however. The act does not assume that it is impossible to educate certain categories of *children* or to accommodate certain degrees of severity in a mainstream school; it merely stipulates that provision in the mainstream *environment* should meet certain conditions. This paper takes "inclusion" to signify (amongst other things) the practice of "special" education in the environment of mainstream schools and classes.

These historical changes indicate the general growth of an outlook which treats the child as a child first, and the disability as secondary. In 1982 approximately 2% of pupils attended special schools, in 1996 the figure was 1.4%.⁴ These figures do not indicate dramatic change. However, the clientele has changed. More children with behavioural difficulties are now in special schools; conversely, mainstream classes may include children with severe learning difficulties who less than thirty years ago would not have been in schools at all.

Inclusion, segregation and social justice

All categories of children, even with the severest learning disability, can now be encountered, usually with special support, in a mainstream class in some part of the country. Yet children with less severe forms of the same disability attend special schools in other areas. Mainstream provision for disabled children is patchy and families seeking inclusion may have to move house in order to obtain it, though legislation excludes no individual or group simply by definition or by degree of severity.

Apartheid

School admissions are effectively controlled at local education authority (LEA) level. Two High Court decisions in 1997 established that segregation on grounds of disability by an LEA may be enforced against parental wishes.⁵ Doctors used to considering ethical questions within the framework of the clinic and the individual doctor-patient relationship may assume that any ethical problem here can be expressed in terms of "best interests": that there may be some individual children who need to be separated either for their own good or for that of other individuals who would be harmed by associating with them. However, an education system consists not only of one-to-one relationships but also of collectivities. Within a putatively "comprehensive" local authority system, for example, legally enforceable separation could be regarded as discriminatory. Despite claims of "best interests", the analogies with apartheid drawn by disability rights activists in this context may not be entirely rhetorical. It is true that much larger amounts of money are spent on the education of statemented children than on their peers and of course much less was spent on black people than on white under South African apartheid. Nevertheless there too separation was legally enforced and justified by "best interests" arguments for both communities. Unless benefit and best interests are to be measured in purely fiscal terms (the administrative convenience of spending those large amounts in historically separate locations rather than in mainstream locations), questions of social justice need to be answered. The ethics of this situation is not inherently problematic, as if there were some self-evident conflict between the best interests of individual statemented children and the demands of social justice, or between educational effectiveness and human rights.⁶ A growing body of literature reports the social benefits to all children of inclusive education and the serious disadvantages of segregated schooling.⁷

As a result of the legislative changes described earlier, doctors still have the legal duty to contribute to the child's statement (even where strictly medical information is no more relevant than for any child without a statement) alongside an educational psychologist and a teacher. However, the locally inconsistent distribution of types of disability or difficulty between special and mainstream schools results less from medical or psychological assessment than from social and political factors: the tradition of the area, the LEA's attitude towards inclusion, administrative convenience in the provision of school places, whether a particular head teacher supports mainstream placement, whether

the child's parents have the confidence to pursue their preference.

It is often assumed that special schools are the only choice for disabled pupils, although it is not clear why segregation as such should offer better social or academic opportunities than special education in a mainstream class. One problem is that utilitarian considerations of harm, benefit and effective outcomes are more difficult to assess by educational criteria than by clinical ones. As educators in the USA have admitted,⁸ educational outcomes are not susceptible to precise measurement, and knowledge about the benefits of inclusion or segregation are not of the same order of certainty as knowledge about the benefits of much medical treatment.

Inclusionists are therefore under the same constraint to be cautious about evidence. Nevertheless, the case for segregation is frequently confused with its historically contingent *de facto* existence. A starting hypothesis free from such contingencies might rather be that children belong together. Given the powerful ties between educational research and the existing system, however, in practice segregation tends to be assumed and inclusionists have to prove their case. They have to argue that *if* inclusion works well or even just passably well by narrow "educational" criteria such as cognition and behaviour, *then* social advantages may accrue such as a reduction in isolation, stigma, and discrimination for the children concerned and an increased maturity and tolerance among their peers. The policy statement of the inclusive LEA in our research project justifies inclusion as a real-world environment for non-disabled children, where all aspects of life including disability are visible and accessible, and inserts inclusion within its equal opportunities policies. Thus the starting philosophical hypothesis is stated in public policy as a conscious political position, attached to arguments about social justice for black pupils and girls.

Illustrations from research

Our research found varying degrees of responsiveness among doctors to the new emphasis on mainstream inclusion. There are fewer differences in the attitudes of doctors between the two areas than between their contrasting LEA policies and personnel. Speech therapists in the largely inclusive East City describe their conversion to inclusion as a principle of justice and as a specialist judgment that permanent access to peers with fully social speech is more helpful to speech development than the relative silence of a special class. Paediatricians and community medical

officers tend to be more phlegmatic and to discuss kinds of schooling with parents in terms of what is available, or they are sceptical of the local policy. Rehana's mother, for example, said:

"So in the [child development] clinic they just laugh at me, they are smiling and looking at my face and saying, 'How do you think, Mrs Sheikh, that Rehana can go to Seymour [mainstream] school?' So I told them. I said, 'Rehana can't hear and she can't see but she likes the children playing around her, so if she is in a special school everyone is quiet and doing same thing so Rehana will not be really happy there'. They said 'All right, is all right, is mother's decision, if you are happy there'."

Rehana has brain damage; Seymour Primary School contains some children equally disabled, while the LEA's one remaining school which caters for severe learning difficulties contains children who are considerably less disabled. We would suggest that the doctors in this case need to consider the LEA's reference to inclusion as a principle of social justice. This need does not necessarily compromise professional judgment; indeed, their implied scepticism about mainstream schooling could be seen as lying outside their clinical expertise.

"Lay" prejudices

In West County, with its high levels of segregation, a research interview found a doctor resisting a request from parents to name a specific residential special school placement; her reason was that a local community health trust doctor cannot comment on educational need. The doctor was aware of the limits of her own authority; however, she stated in general terms that she thought segregation was the only option, denigrating the local high (secondary modern) school. Doctors in more affluent areas may have less stimulus to think about placement in terms of social justice. They can contribute importantly to segregation by suggesting schools which they may know little about. Few doctors observe daily classroom practice in local high schools or special schools, and they tend to send their own children to the different but equally segregated example of grammar and private schools. Their "lay" prejudices against high schools may lead to advising parents against them and therefore in favour of special schools.

In both East City and West County, ignorance (claiming to know when one does not) is not necessarily avoided by limiting specific advice to the strictly medical, since personal preferences may be implied. Doctors also perhaps have an obligation to be wary of how their advice might be

distorted or misused by LEA staff. The statutory requirement for medical advice in statements of special educational need may attach an unjustified "medical" aura to the role of education psychologists and of special school teachers and thus encourage perceptions of segregation as "scientific" and therefore unquestionably correct. This is especially the case with children who have crossover medical-educational labels such as autism. In a unit for autistic pupils in West County, only two of the 17 pupils had clearly autistic symptoms. The rest had certain oddities but in most respects approached the "normal range" of behaviour - making eye contact and warm personal gestures and enjoying imaginative play. As one of our referees has commented, this is the perspective of researchers accustomed to being with disabled children in a non-clinical context; it makes very clear the difficulties involved in discussing discrimination with those not so accustomed, and "the absolute gap" in medical education about understanding and managing disability, as opposed to disease. How much does segregation into special schools and units exacerbate or even stimulate unusual behaviour? These young children had taxi journeys of up to an hour or more from home. They were separated from examples of "normal" behaviour, relationships and learning activities. The staff seemed to perceive the children as ill and incapable of self-control, although at other times they goaded or frustrated them, for example by making someone in a very impatient mood wait until every other child had had their turn, thus suggesting that they saw the child as capable of learning to exert more self-control. Quasi-medical theories, for instance that autistic people dislike change, excused teachers from preparing any new activities.

Evidence of disturbance

All the children's responses, including the kinds of protest which "normal" children would make, were interpreted by the staff as evidence of disturbance, so in effect locking the children into futile attempts to communicate or into silence. A sickness model of behaviour can legitimate teaching standards which would be unacceptable in mainstream schools. In contrast, East City's comprehensive schools (which also contain, in mixed ability classes, those children who in West County would be in grammar schools) included autistic pupils who at times showed extreme symptoms, but who were treated with respect by pupils and staff.

The doctor's role in law since 1981 has been confined to commenting on any special *medical*

factors that need to be taken into account in assessing the whole child, where before they had wide ranging powers over placements. Their statutory powers are now vastly reduced. Informally, however, many doctors still assess and advise as if this were not the case. Where this is welcomed by many LEAs, it is not always due to their ignorance of the legislation. If medical advice assumes a value in social separation and special schools, then an LEA without inclusion policies may be grateful.

Armchair discipline

Medical ethics is much more developed than education ethics, which remains largely an armchair discipline. Children's consent, for example, often highly respected in hospitals, is rarely discussed in educational literature and perhaps even less practised in schools, even "child-centred" ones.⁹ Doctors' close attention to the child's integrity and autonomy during decision-making is seldom matched by teachers. Rules of confidentiality in specifically educational matters are virtually non-existent, either on paper or in practice. However, despite their relative respect for the individual child as patient, few doctors appear to relate school inclusion to ethical respect for children.

Health professionals have to work within LEA policies, and if health advice is misused, or if there is simply no clear inclusion policy, those professionals may feel helpless or believe their hands to be tied, or that it would be unethical to propose that apparently vulnerable children be made guinea-pigs in an unwelcoming environment. But this may not be sufficient reason for resigning personal responsibility or collaborating with a system which may arguably be claiming its own interests as the child's best ones. At the very least there is a dilemma. A moment's thought suffices to show that the number of statemented children for whom placement in a mainstream environment would be *medically* harmful is very small indeed. Even if we add some children involved in "state of mind" assessments or on the social services register, their numbers certainly do not justify the existing system of special day and residential schools which depends for survival on attracting the remainder. If harm for this remainder consists only in the fact that the mainstream environment may be unwelcoming, this is not a matter for medical comment and indeed the assumption that a segregated placement is therefore suitable might even seem to endorse that lack of welcome. The well-intentioned doctor's impulse towards segregation is often prompted by a desire to protect the child. It assumes helplessness in certain children and antipathy from mainstream pupils. Medical

ethics has extensively discussed similar concerns under the heading of paternalism, with its attendant dangers, and the same considerations are relevant when doctors make decisions which impinge on school and social life.

The doctor's influence on school and life careers

Currently health professionals' influence on individual children's schooling and social life-chances may be far greater than they realise. The relevant ethical questions include: how can intervention beyond their formal powers in the administrative pattern of "special needs" harm children and their life-chances? How does intervention beyond their formal powers divert doctors from concentrating their expertise and resources where they are most needed? How can doctors' attempts to confine themselves to what they see as purely health criteria be misused by LEA staff, for example, to counter parents' and pupils' expressed preferences? The problems are illustrated in the following examples.

Although the law prohibits any professional contributions to a statement from naming a school, particular special schools are often identified informally in conversation with parents, as they report in our interviews. In the words of Louise's mother:

"The paediatrician came round when Louise was six weeks old and said there's a full-time place at the special school nursery when she's two... She was only that young, and they were preconceiving and prejudging what she was going to end up like."¹⁰

Attendance at a local mainstream playgroup, nursery or school helps to depathologise the child and the family, and to avoid social exclusion and the sense that the child's disability is unacceptable. Many health authorities concentrate services in child development centres which inevitably tend to concentrate pathologies so that segregation seems a more obvious solution. Though they aim to be multidisciplinary, staff at the centres may not share values. They may give contradictory information to families or cross professional boundaries. Many children are given a placement-related standard psychological test by a clinical medical officer with little or no psychology training. Or a parent may be told by an audiologist: "Well, Maria [a child with spinal muscular atrophy but no hearing impairment] either goes to a special school or she will have to go into care."

Guidance on appropriate boundaries, assessment and prognosis is clearly needed. Psychological

testing of pre-school children with learning difficulties by physicians is often justified as revealing the extra help they will need at school. However, this is usually unnecessary beyond the initial diagnostic stage, because the extra help will be statutorily determined by the LEA's education psychologists. Some children with learning difficulties need *clinical* assessment, but this needs to be clearly distinguished from *educational* testing. Regular observation (but not necessarily psychological assessment) of children with learning difficulties partly due to epileptic conditions might lie within the medical remit; continued assessment of children with emotional or behavioural difficulties might in some cases lie outside it, as the controversy over the use of drugs for attention-deficit hyperactivity disorder shows. These are difficult boundaries, being part of a dynamic process involving not only doctors and clinicians but cultural, political and socio-economic factors. While doctors negotiate these boundaries, regulatory bodies and legislators too must provide a framework.

Questions are raised by the common practice of commenting on a child's social situation in written medical advice in statements. Manley is autistic: "Manley's parents have separated, and he is living with his father for the moment... Manley's father is a Rastafarian and currently has a job organising the transport for a local pop group."¹¹

Does this knowledge contribute to the educational assessment, to what the health authority or LEA may be able to provide or to anyone's understanding of the boy? Is medical time well spent writing it? Might the reference to social aspects of ethnicity and single parenthood not reinforce the perception of Manley as separate from others and therefore more suitable for a segregated school placement than any other child?

Occasional meetings

Occasional meetings with school staff do not enable doctors to assess the effectiveness of the school's or pupils' progress or lack of progress. The language of "special" and "selective", small-class provision implies that staff are "specially" trained and use "special" techniques, though no additional qualification is required for teachers to work in special schools. It can lead doctors as much as parents into believing that children are privileged to be selected, though this may not reflect the actual value of the provision. Advocates of evidence-based medicine criticise health professionals' use of unevaluated clinical interventions, but at least when doctors prescribe drugs and surgery they have some knowledge of the process and outcomes of the treatment. When they informally "prescribe" a particular school

they may mistakenly assume that there is something in education comparable to the Cochrane collaboration, the international network which oversees randomised control trials. There is not yet a national policy, professional or legislative, on inclusion. Most education professionals appear to support it in principle but are passive if not resistant in practice. Placements are often arbitrary: some severely disabled children succeed academically or socially in mainstream schools and some less severely disabled children leave special schools with no local friends and no qualifications.

Many children with chronic illness and disability attend regional or supra-regional or national paediatric centres. Doctors there have contacts with leading specialist schools, but often know little about the growing practice of supported mainstream inclusion in the wide range of LEAs from which the children travel. Some doctors mention the special schools they know, but do not discuss with parents the changes and possibilities since the 1981 Education Act or special services in mainstream schools and classes. In order to give expert information, doctors have to know about local educational provision and about the potential for mainstream provision.

Pragmatic optimism

This is not simply a matter of redressing morally neutral ignorance, but of thinking about medical ethics not only in individual or interpersonal terms, but also in social terms. Schools are aspects of community rather than analogous with hospitals. The surgeon at a teaching hospital who operated on ten-year-old Matthew's imperforate anus went to great lengths to ensure that Matthew's genuine consent was given and to explain the whole process of the operation, with a respect for the autonomy of the child inconceivable in most schools. His paediatrician, however, assumed without question that he would go to a special school in his local area and expressed doubts about the East City mainstream school Matthew now attends without problems.

When health professionals do argue for inclusive education it is often from pragmatic optimism about the potential development of an individual child, and "seeing how it goes for a year or so" rather than from a principle which would affect their consideration of all cases. Their caution is often influenced by the absence of inclusive provision in their area, and the availability of special school places if the first placement is seen to be a failure. Nevertheless, since every degree of disability can be observed in a mainstream school and class somewhere, experience suggests that

inclusion does not have to depend upon judgments about individual potential.

In practice, specialist resources clearly do not *have* to separate disabled children from others. However, can arguments for inclusive provision which are claimed as ethical on grounds of social justice also be respected for their therapeutic benefit to individuals? Children with speech difficulties, for example, have been found to respond more to the stimulus of a normal environment than to the protective quiet of a school for severe learning difficulties. The acceptance and toleration within ordinary schools can then further reduce the stress experienced by their families, with consequent therapeutic benefits to the children's own wellbeing. Children in special schools reported having no friends at home, being bored and lonely in the holidays and also at some of the schools. Lucy, aged 14, spent almost all her time at home in her bedroom. Saying that a doctor had told them she would "only wander off, she wouldn't understand," her parents did not risk allowing Lucy to learn to cope outside the house. Medical statements can become self-fulfilling prophecies. Metim was sad that, having boarded since he was five years old, he had grown away from his family. Richard missed his family at his boarding school and his friends when they moved on to different secondary schools. Some pupils we interviewed did not mind being the only disabled child in a mainstream local school as long as no problems arose; in West County they and the adults knew that if they encountered a problem there was always a special school for that impairment. Susan, for instance, disliked "being mothered and smothered" and took up a special school place. By contrast in East City, where inclusion was not only a positive policy but where most of the segregated schools had been closed, so that no safety-net existed, pupils and adults worked through the difficulties in the mainstream school and eventually commented on its general benefits.

Conclusion

Medical influence on school placement has not diminished as much as the 1981 legislation envisaged. Traditional medical ethics emphasises the individual doctor-patient relationship and the primary duties to do no harm and to base decisions on knowledge rather than opinion. Now that public health ethics involves much more concern for the welfare of communities, the ethical/medical position on schooling and special education needs to be debated and clarified. We suggest that this concern involves a presumption in favour of inclusion and of the transfer of special education

and resources to mainstream schools. When health professionals offer non-medical arguments for segregation, these are no more nor less weighty than those offered by the general public. Yet if doctors limit themselves to strictly medical advice in partly self-imposed ignorance of the socio-political context in which it will be used or misused, this may produce equal harm for the child. Doctors are not obliged to take the education system as it is. They can be agents of change. We hope that this discussion paper will promote much wider debate among clinicians aiming to provide ethical services for children who have disabilities or other difficulties.

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References and notes

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- 5 These cases (*Spendiff v North Tyneside Council* and *Crane v Lancashire County Council*) were discussed ahead of the decision in *Barriers to Justice*. *Newsletter of the Independent Panel for Special Education Advice* 1996 Sept 1-2.
- 6 The Association of Educational Psychologists of the UK adopted a policy on inclusion at its October 1996 conference which elides "effectiveness" with "the inclusion of all children in ordinary schools [as] a basic human right", and refers to the "Salamanca statement" issued by the 1994 UNESCO World Conference on Special Education, which held that inclusion was a human right.
- 7 For a meta-review and substantial bibliography see Booth T. Changing views of research on integration. In: Sigston A, et al, eds. *Psychology in practice with young people, families and schools*. London: Fulton, 1996.
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